

## Short literature notices

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Roberts, M.A. & Wasserman, D.T. (eds.): 2009, *Harming Future Persons: Ethics, Genetics and the Nonidentity Problem*. Dordrecht: Springer. 348 pages. ISBN: 978-1-402056963. Price: € 149, 75

A lot of what we do will affect human beings not existing at the time we act. Although this has been true to some extent for every society, the problems posed by acts with effects on future people become today much more vivid. This is especially visible in societies with highly developed technologies, in particular those operating in the fields of genetics and human reproduction. The volume under review is published in the well known book series entitled “International Library of Ethics, Law, and the New Medicine.” It includes sixteen papers which are grouped in seven parts. Part I (“Can Bringing a Person into Existence Harm That Person?”) and part VI (“Is the Person Affecting Approach Objectionable Independent of the Non-identity Problem?”) consist of one paper only. In their very informative and helpful introduction the editors of this volume make explicit the volume’s purpose. Although it starts with familiar questions like “What are our obligations to not yet existing, or never existing persons?”, “Can a person be harmed by being brought to existence?” or “Can persons be harmed by not being brought to existence?” the main topic of this anthology is a philosophical one called “the non-identity problem”.

There is a widespread assumption that we do have obligations to future persons, especially if their existence depends on our procreative choices, and that we can harm

them. Nevertheless it is hard to spell out this intuition out in a philosophically clear way. One of these problems is that our notion of harm seems to presuppose that there is a currently existing individual suffering a harm and that we can compare the situation of one and the same person to find out whether our course of action has made her worse off or not. The ontology (and semantics) of future or even non-existing entities is very complex and it is far from evident that common sense intuitions will have it all right here without philosophical elucidation. Furthermore many persons do follow person-affecting intuitions as a general (or even meta-ethical) strategy. But if we understand that identity-conditions are not easy at hand in this context the philosophical quarrel arises whether we have to rely here on consequentialism.

The future reader should know in advance that this volume is intentionally and wholeheartedly a philosophical book dealing with conceptual analysis (a lot of papers address aspects of “harm”), the analysis of ethical judgments, meta-ethical questions (the tension between deontology and consequentialism) and the ontology (or semantics) of future and non-existing persons. One of the many ‘strengths’ of this volume is that it includes even a paper (written by Nils Holtug) which doubts that the philosophical non-identity problem does have any impact on our moral questions and intuitions. Besides that Holtug argues that the non-identity problem does not have meta-ethical consequences (e.g. by setting our person-affecting intuitions under pressure); and this is, if I understand their papers correctly, also the message of the two papers written by Philip G. Peters and Seana V. Shiffrin addressing the question whether the non-identity problem affects state regulations of reproductive liberty or reparations for US slavery (both in the United States legal system). So the hopefully actually existing future reader of this volume

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should be interested in philosophical questions and the analysis of basic concepts like “harm”, “future existence” or “identity”. There are concrete or even ‘applied’ ethical problems lurking behind the questions dealt with in these papers, although in nearly each of them it is a long and sometimes even a little bit harmful way to reach them. But having said this as a warning, this book is highly recommended for everyone interested in the impact of our actions on future people—not for philosophers only.

Michael Quante  
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Rehmann-Sutter, C. and Müller, H. (eds.): 2009, *Disclosure Dilemmas: Ethics of Genetic Prognosis after the ‘Right to Know/Not to Know’ Debate*. Farnham, Surrey: Ashgate. 296 pages. ISBN 978-0754674511. Price: £ 60.00

*Disclosure Dilemmas* is a collection of essays exploring the ethics of disclosing prognostic genetic information, which aims to enlarge on the focus of earlier discussions of the subject. As its full title indicates, the book acknowledges the shaping influence on the early debate of *The Right to Know and the Right Not to Know*, edited by Ruth Chadwick, Mairi Levitt and Darren Shickle (1997, Aldershot: Ashgate). But while this might suggest that it constitutes a second edition of the original, *Disclosure Dilemmas* is, in fact, a new volume—one which recognises the limitations of individual rights-based approaches to the subject, while simultaneously avoiding the rhetoric of ‘genetic exceptionalism,’ and which reconsiders the complex issues entailed in genetic information disclosure by means of a hermeneutical approach.

The book is in three parts. Part 1 begins with an overview by Ruth Chadwick of changes in the main trends influencing the ethical debate since 1997, utilising a rights-based framework. Barbara Katz Rothman then questions whether the ‘right to know/not to know’ is the appropriate frame for understanding the nature of ethical dilemmas in genetic screening, calling for examination of the social context that constructs some health problems as ethical dilemmas and others as not. Finally, Hansjakob Müller gives an overview of genetic counselling from a medical professional perspective, cautioning against disclosure of genetic information in the absence of expert medical consultation. This sets the scene for the interdisciplinary approach by which the book is characterised.

Part 2 of the book comprises a collection of papers exploring the reality of cases of predictive genetic testing and disclosure. This reveals the constellation of complex, dynamic ethical issues that may be raised for patients, their

family network and professionals, and the multifaceted and processual nature of information disclosure. The allocation of individual rights and obligations, while not deemed irrelevant, is seen as incapable of yielding a comprehensive understanding of the ethical aspects of decision-making in these various contexts. Correspondingly, the desirability of genetic knowledge, while not denied in some circumstances, is seen as questionable in others, most notably when its predictive value is in doubt.

The legal, moral and ethical responsibilities of those involved in communicating predictive genetic information are considered in Part 3 of the book. This gives rise to consideration of such questions as who owns genetic information and what the obligations to disclose such information are. Of particular note here is Christoph Rehmann-Sutter’s contribution, which draws on evidence and reflections in the book to develop an ethical model for communicating personal genetic information. Rehmann-Sutter’s idea is that the principle of non-directiveness in genetic counselling should be replaced with a more integrative model of “good communication,” retaining the useful elements of non-directiveness (respect) but avoiding the unhelpful elements (pre-emptive individualism).

The strength of *Disclosure Dilemmas* is that it moves beyond individual rights-based liberal discourse, reconfiguring various aspects of the debate on genetic information as a means to better understanding it. Given the complexity and dynamic of the context, the editors do not posit any grand solutions. But they conclude that by combining interpretation of particular ethical questions with general ideas of wisdom and justice, ethical recommendations can be developed. Those seeking a systematic theoretical analysis of the ethics of genetic testing may hope for something more than *Disclosure Dilemmas* delivers. But those looking for informed reflection on a comprehensive range of related issues should not be disappointed.

Jane Wilson  
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Viafora, C.: 2006, *Introduzione alla bioetica*. Milano: Franco Angeli. 512 pages. ISBN 978-8846472625. Price: € 32,50

Corrado Viafora is professor at the Department of Philosophy at the University of Padua and teaches bioethics at the Faculty of Educational Sciences and at the Faculty of Medicine of the same University. In this book he aims to offer a comprehensive introduction to bioethics and to formulate an integrated bioethical theory which does not focus solely on clinical bioethics but highlights its

philosophical foundation in the broader context of global bioethics. The volume deals with bioethics by intertwining three different perspectives: the *foundational level*, which raises difficult questions concerning the concepts of “life” and “person”, as well as the principles and method of a bioethical discussion; the *clinical level*, which faces the methodology of bioethical judgment; the *legal level*, which discusses the criteria to be met by normative regulations relating to the new biotechnologies. The ethical premises of bioethics are addressed, as well as issues in clinical bioethics, in the public debate on life decisions, in the deliberative method adopted by ethical committees.

In the first part of the volume the author acknowledges his debt to the work of Mounier, Ricoeur, Jonas and Ladrière, identifying his own position as an ethical-founded personalism based on the principle of human-dignity. Viafora succeeds however, in maintaining an open dialogue with bioethical standpoints stemming from other philosophical traditions, such as the consequentialist and the deontological ones.

Inspired by Diego Gracia’s work, the second part of the volume shows how the practices in clinical bioethics ought to comply with the ethical-argumentative method which puts the autonomy principle as second, after the principle of beneficence. Always from a personalistic perspective, the third part discusses the ethical issues in decisions concerning the beginning and end of life. The book also deals with the ethical aspects of assisted reproductive technologies and of euthanasia, as well as practices of scientific experimental research. The author compares the varied European regulations with the Italian ones and invokes the “culture of limit”, and the application of the “precautionary principle”, which is recommended, even if it still lacks a proper definition. The deliberative method to be used by ethical committees is dealt with in the fourth part, where Viafora shows the challenge of elaborating a method suited to our pluralistic society. A historical and theoretical overview of ethical committees is presented by comparing the North-American experience with the European and particularly with the Italian one.

Two key arguments of the author’s main thesis have been further developed by him in later essays. A discussion about the use of the human-dignity principle when dealing with clinical bioethics appeared in a miscellaneous work in 2009, such as a contribution about the right to a dignified death, where the author presented four grounds to support the ethics of care for dying patients. See in particular: “Argomentare con la dignità umana nell’ambito della bioetica clinica” (in: E. Furlan, ed., *Bioetica e dignità umana. Interpretazioni a confronto a partire dalla Convenzione di Oviedo*, Milan, Franco Angeli, 2009); “Il diritto a morire con dignità: quattro tesi sull’etica dell’accompagnamento” (in: A. Argiroffi et al., eds., *I diversi volti dell’eutanasia*.

*Prospettive teologiche, etiche e giuridiche*, Roma: Aracne, 2009).

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Takala, T., Herissone-Kelly, P., and Holm, S. (eds.): 2009, *Cutting through the surface. Philosophical approaches to bioethics*. Amsterdam: Rodopi. 278 pages. ISBN: 978-9042027398. Price: € 67, 99

If the field of bioethics were music, then this book would certainly be rock’n’roll. It certainly rocks and it is rebellious. That was my very first impression after I had read the foreword by M. Häyry, and it was my very last thought, after having been convinced by T. Airaksinen that we are all moving towards a future of cyborg-societies. But first things first: The editors state in their preface that this wonderful collection is a book to celebrate Matti Häyry’s 50th birthday. Certainly, as you start to read, you can easily spot that the authors have known each other for years. As they celebrate their philosophical approach to bioethics, the authors are very self-reflective, and at times quite ironic. One sometimes has to smile when they refer to each other’s arguments, quote each other’s texts and recurrently manage to put Häyry’s work at the centre of the discussion. However, that is exactly what makes the book so appealing. You, as a reader, feel as if you were part of the discussion, part of a late-night birthday party with friends that share the same interest. And even if you are new to the party, you truly learn a lot, as all the authors take their time to thoroughly ground their ideas and arguments in an impressively coherent style. It is this coherent style that distinguishes this book from other loosely edited volumes. In this book, all 23 texts perfectly fit together.

So, what is the book about? It is about the philosophical side of bioethics, and it clearly argues for philosophical reflection in the field of bioethics. As S. K. Hellsten puts it in her text: “...today we can detect two main polarized ways of doing “bioethics”: abstract theoretical speculation detached from reality on the one hand, and political pragmatism on the other. In order to build a bridge between these extremes, there is a need to bring reflection and argumentation back to bioethics” (p. 17). The discipline of philosophy can bring back this reflection, it can help to dig deeper, and can help to “cut through the surface” as the title of the book indicates. Philosophy is not “mere rhetoric” (Takala et al., p. 1), but rather “reflection and logic to make sense out of entangled arguments and confusion in the use of concepts and to understand the differences of our values” (Hellsten, p. 17). In a truly philosophical manner, the book starts with three chapters that tackle precisely these kinds of introductory issues by asking the question

“What is bioethics and where should it be going?” (we talk about the authors S. K. Hellster, S. O. Hansson and H. Lesser here). The following chapters then investigate some core issues in methodology, and how to proceed in bioethics from different viewpoints (V. Launis, J. Räikkä, P. Louhiala and L. Toiviainen). We then move on to a block of chapters that deal with the concepts of dignity (S. Woods), autonomy (N. Scott), precaution (M. Parker and P. Vineis) and solidarity (V. Arnason). Simon Woods helped me to reconcile with the slogan-like concept of dignity, by persuading me that “... dignity requires particular regard to ‘bodily’ treatment (...) and care upon the concept of self-esteem” (p. 76). Finally, Sören Holm ends this row of chapters by eloquently addressing a potential future problem for us all (innocently wrapped up in a lyric of the Beatles): “Will you still need me, will you still feed me, when I am 64?” Section four of the book focuses widely but quite provocatively on medical research and eradicating human diseases (M. Battin et al., J. Harris and R. Rhodes). What follows in section five is a special collection of chapters in the area of reproductive medicine that build on some provoking arguments of Häyry. He once showed that one could argue that human procreation is “irrational” and even “immoral”—there are remarkable responses and intriguing ideas in this book in reply to this challenging contention (F. Ruokonen and S. Vehmas, F. Leavitt, R. Ashcroft, R. Bennett and T. Buller). The book ends nicely with some philosophical responses to the debate around the field of enhancement (written by L. Bortolotti, H. A. Gylling and T. Aikraksinen).

I had high expectations with regard to this edited volume. Why these expectations? Well, I would call myself a bioethicist, I have studied philosophy, I love philosophy, and I currently work as a clinical ethicist in a University hospital, dealing with practitioners on a daily level. I am confronted with some of the core issues of this book on a daily level. The physician often does not seem to trust me, as I am a philosopher rather than a clinician, and have obviously never “seen a patient die” (cf. Louhiala p. 55). And I often find myself trapped in prejudices myself. Some physicians, I tend to think, may have never reflected upon conceptual definitions, and might even consider ‘epistemology’ to be a foreign language. So I truly hope that this book can help bridge some conceptual, empirical and analytical gaps in the amazing field of bioethics. However, bioethics is still in its infancy, it is in the process of unpacking and applying concepts. We need the discipline of philosophy here to help do this job.

Rouven Porz  
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López de la Vieja, M.T., Velayos, C. (eds.): 2008, *Educación en bioética. Donación y trasplante de órganos. Bioethical education. Organ procurement and transplantation*. Salamanca: Ediciones Universidad de Salamanca. 333 pages. ISBN: 978-84-78003235. Price: € 18,00

This volume, edited by María Teresa López de la Vieja and Carmen Velayos, gathers a number of bilingual articles (in Spanish and English/French) on the ethical issues arising from organ transplantation. The book is the result of a Workshop on bioethical education and transplantation ethics that took place in May 2007 in Salamanca, within the context of a collaborative European project (*Edubioethics: Bioethical Education in a Multicultural Environment*). Participants from Spain, France, Switzerland, Italy, Lebanon, Romania, Malta, Costa Rica, the United States and Canada took part in the Workshop. The volume contains a selection of the papers presented at that event and includes a DVD with the lectures given by all the participants.

José María García Gómez-Heras introduces the volume with a chapter on the role of education in bioethics and the project of *Edubioethics*. The first part of the book is focused on fundamental questions regarding organ procurement. Laura Palazzani examines the bioethical criteria for patients’ selection in organ allocation. María Teresa López de la Vieja analyzes the ethics of non-lucrative organ donation based on altruism and emphasizes the gender imbalance among living donors and recipients. Carmen Velayos offers a critical point of view on moral anthropocentrism in xenotransplantation. Stéphane Bauzon reflects upon the possibilities offered by nanotechnologies in organ transplantation and the ethical issues arising from them. The second part of the book is dedicated to international issues related to organ transplantation. Mark Aulisio examines the ethical challenges arising from the growth of living organ donation in the US which must be met if living organ donation is to be done responsibly. Béatrice Ioan and Vasile Astarastoe discuss the history and legal issues of organ and tissue transplantation in Romania. Marie-Chantal Fortin presents the dilemma Canadian physicians face when treating patients who have bought a kidney overseas. Finally, David Rodríguez-Arias offers a critical analysis of the Spanish Model of organ transplantation and its success in having the highest rates of organ donation in the world.

In addition to the papers already mentioned, the DVD contains lectures by the following authors: Manuel Urrutia, Stuart Youngner, Lazare Benaroyo, Marie-France Mamzer-Bruneel, Emmanuel Agius, Alberto García, Fadi Abou Mrad, Paolo Girolami, Paolo Simone, Marco V. Boza and

David Paredes. These contributions are completed by a specialized bibliography on transplantation ethics and an appendix constituted by a selection of legal regulations on organ transplantation.

This excellent book puts in evidence the difficulties of balancing, on the one hand, the consequentialist need of procuring as many organs as possible to satisfy organ demands and, on the other hand, the need to comply with the moral requirements of autonomy, non-maleficence, beneficence, and justice, as well as cultural, religious and political traditions. The ideal is to achieve models of organ procurement and transplantation which may be therapeutic but respectful, efficient but transparent. In other words, international guidelines on organ transplantation aim to fulfil the requirements of governance currently demanded by citizens across the globe. In order to realize this ideal, books like this one, which develop a reflection on these complex issues and emphasize the value of the educational dimension of bioethics, are of the utmost importance.

Carissa Véliz  
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Bompiani, A.: 2009, *Consiglio d'Europa, diritti umani e biomedicina. Genesi della Convenzione di Oviedo e dei Protocolli*. Roma: Studium. 375 pages. ISBN 978-8838240737. Price: € 32.50

Adriano Bompiani has extensive experience working in international committees. His latest book is entirely devoted to the genesis of the European Convention on Human Rights and Biomedicine—also known as the “Oviedo Convention”—and its additional protocols, including the most recent one on genetic testing for health purposes. Bompiani is a Catholic physician and Emeritus Professor of Obstetrics and Gynecology in Rome. He has served as a member of the Italian National Committee for Bioethics since its foundation in 1990, and acted as its first president. As a member of the CDBI (the Steering Committee on Bioethics of the Council of Europe), he has been directly involved in the drafting work of the Oviedo Convention.

The volume offers an introduction to the Council of Europe system and the internal drafting procedures, which are extremely clear and useful to all readers that are not familiar with the working method of the Strasbourg organization. He also offers a general overview on the international sources that deal with human rights and that have represented the background context for the drafting bodies. International legal documents are again considered in detail when analyzing the making of specific instruments. The few mistakes in the legal terminology that occasionally

occur have no impact on the quality of the work and are outweighed by the capacity of the author to depict the dynamics of negotiations and to describe the committees and organs implicated in the drafting and the influence they had on the final wording.

Most of the book is descriptive of the treaty-making procedure of the Oviedo Convention and its protocols and recommendations. The author is sensitive to the position of the parties that advocate a strong protection of human life, so that when reading the book, you learn about the clash of different views on the legal status of the embryo and on the role of research. The reader arrives at an understanding of how the Council of Europe reaches compromises in several occasions and how the goal of a 2/3 majority of consensus may require to set aside disputed issues that are nevertheless relevant. For instance, the lack of a common definition of concepts and terms turns out to be a negotiated solution because it widens the margin of appreciation of the contracting parties. Also the option of reverting to additional protocols is a means to work on controversial aspects separately and to avoid slowing down the drafting of the main convention.

The final chapter contains some concluding remarks. Bompiani considers that the Convention and related documents represent a success in underlining the common values of European and even non-European countries (as the Convention is also open to non-Council of Europe member States). Art. 2 epitomizes this attainment when it states the primacy of the single human being over society or science. Another example is the central role given to the patient in fostering autonomy regarding her own health, despite the differing views on the relevance of consent and advanced declarations. The author refutes some critiques to the Convention and states that most of them “stem from an insufficient knowledge of the real working conditions and from the principle of ‘incrementality’” established by the Council of Ministers in 1971 for attaining its objectives (p. 256). He eventually acknowledges that some issues as settled are still unsatisfactory and meet with negative commentaries (e.g. status of the embryo, biomedical research and consent, genetics). However, they would need to be judged in view of the political context that had to craft several compromises. Among others, he also counters the critique to the strong prohibition of human cloning (perhaps not convincingly, p. 262).

Bompiani argues that the discretion accorded to the states with regard to the extent to which access to health services should be granted is in line with other international instruments. Bompiani's closing thoughts are devoted to the latter issue. He points out that even though this compromise of the Convention is problematic there is a growing consensus towards an increase in the rights of the

European patient. The whole systems he describes represents a sort of political *acquis* that will contribute together with other international and European instruments to setting the agenda for a common legal code of the rights and duties both of patients and medical practitioners. The

Council of Europe—one can agree—could again lead the way.

Alexander Schuster  
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